
Welcome to FH Europe Foundation's February 2024 edition of Heart Beat.



FH Europe Foundation February 2024 Heart Beat News

Today is the rarest day of the year, and we are celebrating Rare Disease Day with the message “Rare is Strong, Proud, and Many!”. On this occasion, we have prepared for you several interesting updates including publications on HoFH and FCS and an invitation to an unusual webinar “Make It or Break It” which will explore communication in rare diseases. Most powerful, however, are the stories told by our HoFH and FCS Patient Ambassadors from across the world.

In this edition, we wish to share the latest updates on the progress in FH paediatric screening in Bulgaria and Germany and the work done in the secondary prevention space.

And as of tomorrow, we kick off the Lp(a) awareness activities. There is a lot of excitement generated within our network so check out what we have prepared for you with the “Ask me anything about Lp(a) campaign” in collaboration between the world expert on the topic and our patient Ambassadors.

But there is a lot more to be excited about including a cutting-edge project in precision medicine. Oh, and one more thing. Our Team is growing so say hello to Grainne!

Enjoy reading!



Rare Disease Day 2024

Support, collaborate, share

Today, on February 29, 2024, we celebrate Rare Disease Day and join with other individuals, organizations, and stakeholders in loudly proclaiming the message: Rare is Strong, Proud, and Many!

Issues affecting patients of one rare disease are commonly echoed across the wider rare diseases community. Throughout the entire month of February, we have used our social media profiles to share key challenges and issues affecting people living with rare diseases. We set them against the lived experience of Patient Ambassadors from our community, living with FCS and HoFH. Make sure to watch some of the videos specially prepared by the HoFH and FCS Ambassadors on the occasion of the Rare Disease Day.

The HoFH and FCS Ambassadors have found much common ground since they met for the first time in person at the Annual Network Meeting in November of 2023. As a result of their rich discussions, a dedicated session has been cocreated to address challenges related to communication in rare diseases. Check out the idea behind the "Make it or Break it" webinar which we will host on March 7 (read more information below).

Read more about it [here](#).



Make It or Break It: Communication in Rare Diseases

We invite you to join a special webinar on March 7, 2024, from 6 to 7 pm CET. Join us as HoFH and FCS Patient Ambassadors and caregivers share their experiences, discussing how communication about their rare diseases has impacted their lives, health attitudes, and interactions with others. Featured speaker Natalia Vázquez, a research psychologist and Founder and Scientific Director of [Fupaeh](#) (the Applied Psychology Foundation for People with Orphan Diseases) in Argentina, will share evidence-based tips on good communication in this area. The webinar will be moderated by Jill Praver, our rare diseases project manager.

For more information and to register, click [here](#).



Bamberg Europe Rare Diseases Summit in Madrid

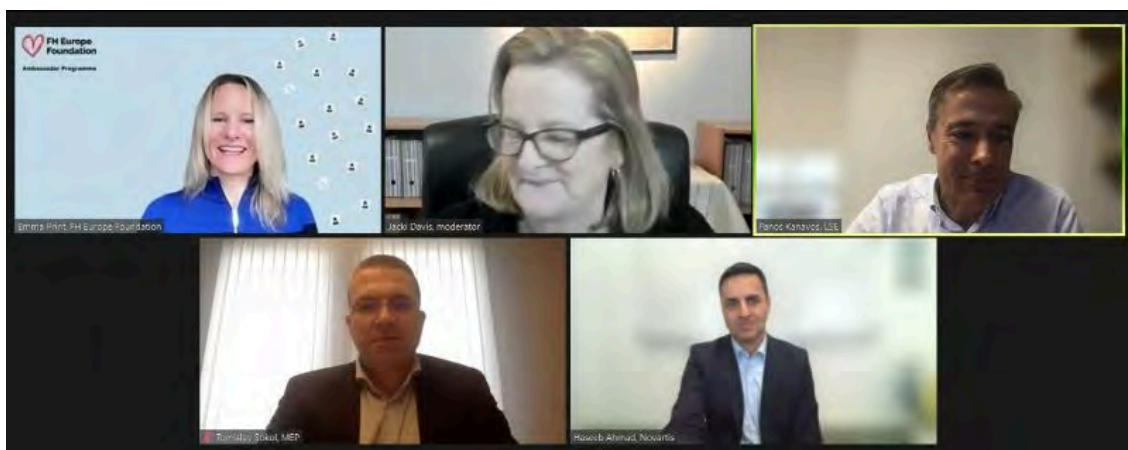
No better day than Valentine's Day to advocate for patients with rare diseases, especially those leading to heart-related health issues. On February 14, members of our team were actively involved in the European Rare Diseases Summit hosted by Bamberg Health in Madrid, Spain.

The aims of the summit were to explore important developments and issues in diagnosing and treating rare diseases in Europe. This was done through a series of panel discussions and individual talks led by multidisciplinary experts in the field. The event also addressed the obstacles faced in ensuring prompt and fair availability of specialized medications, known as orphan drugs. Additionally, it highlighted European efforts in facilitating access, advancing research, and promoting innovative programs to enhance the well-being of patients with rare diseases. The panellists discussed how to improve and learn about Government Plans, Access & Financing, Clinical Research and Innovation, Artificial Intelligence and Data, and Social & Patient.

Magdalena Daccord, in the opening panel dedicated to national plans for rare diseases, drew attention to the need for leveraging opportunities within other disease areas and expressed ambitions to have such plans so that patients with rare disease are not left behind. She specifically referred to the example of the ongoing efforts for cardiovascular health plans and the need incorporate needs of patients with rare CVDs.

Our new Partnerships and Development Lead, Grainne Crowley, moderated the closing panel on the Management of Rare Diseases, Research Networks & Reference Centers. She did a fabulous job ensuring that, despite the highly technical discussions, the importance and the value of early patient and family engagement was emphasised.

The event offered a great platform for multistakeholder exchanges, learning and networking.



Patient Voice Represented at the EFPIA Virtual Event by Emma Print

On February 20, our very own Patient Ambassador and Community Engagement Manager, Emma Print, spoke at a virtual event organised by EFPIA (the European Federation of Pharmaceutical Industries and Associations). She represented the patient voice, sharing the space with Panos Kanavos, Associate Professor of International Health Policy at the London School of Economics and Political Science; Tomislav Sokol, Member of the European Parliament, EPP Group, Croatia, and Haseeb Ahmad, President of Novartis Europe.

Recently published research by the London School of Economics (LSE), commissioned by EFPIA's Cardiovascular Health Platform, demonstrates that if 70% of people living with cardiovascular disease could have their risk factors better managed, 1.2 million deaths in the EU could be averted over the next ten years. For example, reducing LDL-cholesterol levels by just 1 mmol/L has been shown to reduce all-cause mortality by 10%. Cardiovascular disease still remains the number 1 killer in Europe, costing the EU 282 billion euros per year. In addition to mortality, morbidity and cost, the experience of a heart attack or stroke can also have a profound and lasting impact on the patients' quality of life of those affected, as well as their families or carers. We support the call from the European Alliance for Cardiovascular Health (EACH) for a "European Cardiovascular Health Check" to be incorporated into member states' national cardiovascular plans.

You can watch the recording of the event [here](#).



Lp(a) Awareness Day campaign – join, collaborate, share

Tomorrow, on March 1, we will start our social media campaign for the third Lp(a) Awareness Day, which officially takes place on March 24. Globally, 1 in 5 people have elevated levels of Lp(a), yet less than 1% of people have had their levels measured. As an independent risk factor for cardiovascular disease, it is critical that we raise awareness amongst the public and also our healthcare professionals.

We and our community will be sharing posts on social media throughout March, helping to increase your knowledge about Lp(a). Access to these posts, so that you can share them on your personal social media accounts, will be shared in the first week of March. Together our voices are stronger!



Ask me anything about Lp(a)!



Dr Pia R Kamstrup
Denmark



Prof. Florian Kronenberg
Austria



Dr Jaimini Cegla
UK



Aedan Kaal
The Netherlands



Emma Print
UK



Submit your questions
from 7 to 20 March 2024



Register for the webinar to get
your answers on 21 March 2024

Ask me anything about Lp(a) Webinar

Join us on March 21 at 18:00 CET for a special "Ask Me Anything" webinar focused on Lp(a), an essential but often overlooked factor in cardiovascular health. As part of our efforts to advocate for Lp(a) awareness day on March 24, our panel of experts will be on hand to address your questions and provide insights into this critical biomarker.

You will have the opportunity to ask questions through a special form that we will share with you on March 7. Don't miss this unique opportunity to deepen your understanding of Lp(a) and its impact on heart health.

Register to the webinar [here](#).

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Instituto Nacional de Saúde
Dr. Ricardo Jorge (INSA)

BioISI

UNIVERSITY OF HELSINKI

Inserm

UR UNIVERSITÉ DE LA RÉUNION

FH Europe Foundation

WEBINAR

PerMed FH – An introduction to an innovative precision medicine research project for FH

26 March 2024 17.30-18.30 CET

Prof. Mafalda Bourbon
National Institute of Health
Dr. Ricardo Jorge (INSA)

Prof. Gilles Lambert
Université de La Réunion -
Inserm

Simon Pfisterer
University of Helsinki,
Monocyte Ltd

Prof. Eric Sijbrands
Internal Medicine
Erasmus

Magdalena Daccord
FH Europe Foundation

PerMed FH – an Innovative Research Project for Precision Medicine in FH Explained

We invite you to join the upcoming webinar on March 26, 2024, where you will get valuable information and insight on the innovative European project

"PerMed FH – Personalizing diagnosis and treatment for Familial Hypercholesterolemia", which promises to revolutionize the diagnosis and treatment of Familial Hypercholesterolemia (FH) and represents a significant leap forward in FH research.

The webinar speakers **prof. Mafalda Bourbon**, a senior researcher at the National Institute of Health, Portugal (INSA); **Prof. Gilles Lambert**, Professor in Biochemistry at the University of La Réunion Medical School – Inserm (France); **Simon Pfisterer**, Principal Investigator at the University of Helsinki and Chief Scientific Officer, Monocyte Ltd.; **prof. Eric Sijbrands**, Professor of Vascular Medicine; and **Magdalena Daccord**, CEO of the FH Europe Foundation, will talk about the purpose of the project, the benefits for patients, and the project's timeline and work packages.

Read more about it and register [here](#).

The graphic features the FH Europe Foundation logo on the left. The main title is "Members of the Lp(a) International Task Force". A vertical blue bar on the left is labeled "Core group" and lists four members: Magdalena Daccord, Prof. Florian Kronenberg, Dr. Marius Geantă, and Nicola Bedington. To the right, there are two columns of members, each with a portrait and name. The first column includes Prof. Zanfina Ademi, Dr. Zhenyue Chen, Dr. Jean-Luc Eiselé, Bogi Eliassen, and Prof. Mariko Harada-Shiba. The second column includes Dr. Andrija Janićević, Dr. Pia R. Kamstrup, Lena Lymperopoulou, Marc Rijken, and Dr. George Thanassoulis. At the bottom left, there are social media handles (#MeasureLp(a), #Lp(a)TF) and a QR code. At the bottom right, contact information for Magdalena Daccord and Nicola Bedington is provided.

Core group

- Magdalena Daccord**
FH Europe Foundation
The Netherlands/Europe
- Prof. Florian Kronenberg**
Medical University of Innsbruck
Austria
- Dr. Marius Geantă**
Centre for Innovation in Medicine
FH Europe Foundation
Romania
- Nicola Bedington**
Mibivata Partners GmbH
FH Europe Foundation
Austria

Members of the Lp(a) International Task Force

- Prof. Zanfina Ademi**
Centre for Medicine Use and Safety,
Faculty of Pharmacy and
Pharmaceutical Sciences
Austria
- Dr. Zhenyue Chen**
Department of Cardiovascular Medicine,
Qilin Hospital, Shanghai Haotang
University School of Medicine
Shanghai
- Dr. Jean-Luc Eiselé**
World Heart Federation
Switzerland/Globa
- Bogi Eliassen**
Copernicus Institute for Futures Studies
Denmark/Global
- Prof. Mariko Harada-Shiba**
Cardiovascular Center, Osaka Medical
and Pharmaceutical University
Japan
- Dr. Andrija Janićević**
Hoch Diagnostica International
Switzerland/Globa
- Dr. Pia R. Kamstrup**
Copenhagen University
Hospital
Denmark
- Lena Lymperopoulou**
Novartis
Switzerland/Globa
- Marc Rijken**
KLJF
Lipid Clinic, Ambassador
The Netherlands
- Dr. George Thanassoulis**
McGill University Health Centre
Canada

Follow us on social media
#MeasureLp(a)
#Lp(a)TF

Learn more and
join this global
initiative!

For more information contact:
Magdalena Daccord, md@fheurope.org, +41 78 908 42 52 (CH)
Nicola Bedington, nba@fheurope.org, +43 699 110 64 169 (AT)

Advancing the Lp(a) International Strategy

The Lp(a) International Taskforce has now expanded with additional members from Japan – Prof. Mariko Harada-Shiba and China - Dr Zhenyue Chen. The International Taskforce members will meet in person in Lyon, France, ahead of the European Atherosclerosis Society Annual Congress. The group was officially established in April of 2023 with the goal of making measuring Lp(a) a norm globally in an effort to prevent CVD in people with high levels of lipoprotein (a). In relation to the upcoming Lp(a) Awareness Day on March 24, we will have a dedicated session introducing the International Taskforce and its goals to the wider community.

WELCOME TO THE TEAM



Gráinne Crowley

Partnerships and Development Lead

Gráinne Crowley joins the FHEF team as Partnerships and Development Lead

Our team is expanding, and it is our pleasure to announce that Gráinne Crowley joined our team as FHEF Partnerships and Development Lead on February 1, 2024. Gráinne brings over 15 years of experience in patient advocacy and health policy gained within the biotech industry. In her role as Partnerships and Development Lead, she will be responsible for developing and fostering meaningful relationships with the wider health industry, including life sciences, MedTech, and diagnostics, as well as the emerging players in the health innovation space. These entities share a common mission with FHEF to further our Foundation's aims and objectives. Moving forward, Gráinne will lead the Industry Roundtable, while ensuring all our activities align with the governing compliance and ethics rules, as well as agreements in place between FHEF and our Industry Partners.

We warmly welcome Gráinne to the Team and the FH Europe Foundation community.

Read more about it [here](#).

[How to pronounce the Grainne?](#)

**NETWORK
NEWS**

Austria - FHchol Austria

Gaby Hanauer-Mader Memorial Hike in March

Join FHchol Austria for the Gaby Hanauer-Mader Memorial Hike on Saturday, March 16, 2024! The group will convene at 10:00 a.m. at the market square in Perchtoldsdorf. Their leisurely hike through the picturesque Perchtoldsdorf Heath will take them to the Kammersteiner Hütte, where they'll stop for a

delightful lunch break.

It's a perfect opportunity for a cozy get-together and a chance to unwind after the hike. Everyone who can't join the hike is warmly welcome to participate in the afternoon festivities!

Read more about it [here](#).

Prepared by FHchol Austria



Bulgaria - Federation Bulgarian Patients Forum

Bulgaria hosted a high-level meeting on FH paediatric screening

A landmark event titled "Screening and Prevention of Dyslipidaemia – a Priority of Health Policy in the Republic of Bulgaria" was held in the Bulgarian National Assembly on February 27.

The high-level roundtable, hosted by the Health Committee, brought together the Health Ministry, FH patients and advocates, representatives of various medical societies, the Bulgarian Medical Association, the National Health Insurance Fund, and the industry to discuss the need and urgency to implement a dedicated set of strategies to tackle Familial Hypercholesterolemia (FH) — a serious cardiovascular disease risk factor. This initiative is part of the national cardiovascular disease prevention effort and the broader health plan.

It is estimated that there over 23,000 people have heterozygous FH with an additional 23 individuals suffering from its severe and rare form - homozygous FH. However, a set of existing different barriers exacerbates an already very

dramatic situation in the country for those affected.

These were the main asks raised at the event:

- Shifting FH screening to the first decade of life, preferably at the age of 6.
- Combining it with relatives' screening of diagnosed children, coined as (reverse) cascade screening.
- Reviewing guidelines to make innovative therapies accessible at the primary prevention level.

The meeting, initiated and organised by the Federation Bulgarian Patient Forum led by Ivan Dimitrov, was the first substantial step towards changing those statistics and implementing strategies which will reap dividends for Bulgarians. The discussions were attended by Magdalena Daccord, Prof. Albert Wiegman, Prof Urh Groselj and Dr Marius Geanta as international expert speakers.

Read more about it **on our website (coming soon)**. In the meantime, [read the official press release](#) by the Bulgarian Parliament in Bulgarian and in English.

Prepared by Federation Bulgarian Patients Forum

Italy - AISC APS

AISC APS 2024 Activities

AISC APS remains committed to its vital awareness campaign focused on preventing cardiovascular diseases and educating the public about heart failure. This year, the campaign will be conducted in pharmacies across Italy and through the AISC traveling clinic bus, starting in early June. These initiatives are crucial as they often reach citizens who may not realize they are at risk for heart-related conditions, helping to improve awareness and identify potential health issues early on.

AISC has also embarked on an ambitious five-year project as part of the European initiative "BIOmarker-based Diagnostic Toolkit to Personalize Pharmacological Approaches in Congestive Heart Failure." This project, generously funded by the European Commission with over 9.6 million euros, aims to develop a user-friendly device for outpatient use. This device will simplify patient testing, optimize therapy and resources, and ultimately reduce hospitalizations due to heart failure, a leading cause of hospital admissions.

Furthermore, AISC has launched a new study focusing on the impact of glipizide treatment on diabetic patients at risk of heart failure in general medicine. This study involves monitoring clinical indicators at General Practitioner offices and pharmacies, with the support from AISC professionals.

Lastly, on February 15, AISC APS participated in a crucial hearing at the "Ministero per le Disabilità". The discussion centered around establishing a technical team to advocate for improved legislative support for family caregivers, recognizing their invaluable contribution to patient care and well-being.

Prepared by AISC APS

Hungary - SZÍVSN

Reflections on World Patients' Day

On World Patients' Day on Feb 11, SZÍVSN honoured those facing illness, drawing inspiration from Sándor Márai's words in "Weed". Márai's reflection on the restorative power of illness encourages proactive self-care, advocating for voluntary breaks, and nurturing the body's needs. SZÍVSN echoes the importance of self-discovery and solidarity in navigating health challenges.

Read more about it [here](#).

Empowering Communities: Ilona's Journey with SZÍVSN

Ilona, a seasoned healthcare professional, has embarked on a new role as coordinator for SZÍVSN, driven by her passion for serving marginalized communities. With over two decades of experience, she navigates the challenges of healthcare access and awareness in underserved regions. Starting her career at Matieskalka Hospital, Ilona witnessed firsthand the barriers to healthcare faced by many. Determined to make a broader impact, she spearheaded projects totalling millions of euros and organized community events to uplift those in need. Despite daunting obstacles, Ilona remains committed to her mission. Through initiatives like healthcare screenings and employment programs, she addresses critical needs while empowering individuals to take charge of their health. Ilona's dedication exemplifies SZÍVSN's mission of compassion and solidarity.

Read more about her inspiring journey [here](#).

Prepared by SZÍVSN

UK - Heart UK

Heart UK's Heart Month

In February 2024, Heart UK spearheaded a compelling campaign during Heart Month, shedding light on critical issues surrounding heart health. Through their dedicated efforts, Heart UK addressed the concerning statistic revealing that

nearly 1 in 2 adults in the UK is affected by high cholesterol.

Throughout the month, Heart UK engaged individuals in various activities aimed at promoting heart health awareness and raising vital funds. Participants were encouraged to take on personalized challenges, such as running or walking 46 miles, swimming 46 lengths, performing 46 acts of kindness, or doing 46 push-ups or sit-ups a day.

Heart UK's initiatives aim to spark important conversations about heart health and empower individuals to take proactive steps in managing their cholesterol levels. By sharing their message and encouraging participation in the Heart Month challenges, Heart UK has made significant strides in raising awareness and fostering community engagement.

As we reflect on Heart Month, we commend Heart UK for their impactful efforts in advocating for heart health and look forward to continuing to support their mission in the future.

Read more about it [here](#).

Prepared by Heart UK

Global Heart Hub

Empower Webinar: Mental Health & Wellness, Living with Cardiovascular Disease

Global Heart Hub and their Polish affiliate, Serce na Banacha, are excited to present this session on mental health and wellness for all those living with or affected by cardiovascular disease.

When: March 13 | Time: 12:00 EST | 16:00 GMT | 17:00 CET

We will hear from certified clinical psychologist Dr. Anna Mierzyńska, whose expertise is in clinical health psychology and cardiac psychology. Patient advocates Marcin Ruciński (Poland) and Jackie Ratz (Canada) will shed light on mental health challenges and strategies from the patient's perspective, as well as discuss the benefits of finding and building communities.

Find out more about this webinar and register [here](#).

Read more about it [here](#).

Prepared by Global Heart Hub

Germany - free FH screening for children in Lower Saxony

On February 14th, VRONI launched, extending the successful model of [the VRONI study](#) in Bavaria, free FH screening for children aged 5 to 14 will now be available in Lower Saxony. This initiative aims to safeguard even more young hearts.

Read the full press release [here](#).

Furthermore, on February 22, the Federal Joint Committee issued a decision on the commissioning of the Institute for Quality and Efficiency in Health Care: Assessment of a Screening Programme for the early detection of Familial Hypercholesterolaemia in children and adolescents in Germany.

This means a great development in efforts towards having a more systematic, nationwide approach to early screening.

More information is available in the [official press release in German](#).

PATIENT STORIES

Rare Disease Patients' stories

This Rare Disease Day, take a moment to listen to the inspiring stories within our network, where our FCS and HoFH ambassadors courageously share their personal journeys, offering an intimate glimpse into the challenges, fears, and hopes they encounter daily.

Through these insightful videos, gain a deeper understanding of life with rare diseases like FCS and HoFH. Each story embodies resilience and strength, serving as beacons of hope and perseverance for others facing similar battles.

Join us in honouring Rare Disease Day by exploring these powerful narratives. By lending an ear to these voices, we can foster empathy, awareness, and support within our community, ensuring that no one faces these challenges alone.

Watch the videos on our YouTube Channel

EURORDIS

EURORDIS Black Pearl Awards 2024 Celebrate Rare Disease Champions

EURORDIS-Rare Diseases Europe proudly announces the successful conclusion of the Black Pearl Awards 2024, which honours champions of the rare disease community.

The ceremony, held both in Brussels and online, brought together hundreds of individuals from across Europe and the international rare disease community. Attendees included patient advocates, healthcare professionals, industry stakeholders, policymakers, and artists, representing 40 countries.

As today is Rare Disease Day, the Black Pearl Awards serve a dual purpose. They recognize outstanding contributions and unwavering commitment within the rare disease community while also fundraising for the Rare Disease Day campaign, directly supporting those affected by rare diseases.

Read more about it [here](#).

As a community that supports two rare lipid diseases, HoFH and FCS, we were thrilled to participate in the online festivities and had an amazing time celebrating with those who were able to attend in person. We are inspired by the dedication and passion of everyone who works to make a difference for the rare disease community. Don't forget to check out our support campaign on social media and share your own story. Together, we can make a positive impact and create a brighter future for those affected by rare diseases.



EAS

7th EAS Paediatric FH Symposium in Lyon, France

Together with three international Patient Ambassadors, we will be presenting at the **7th EAS Paediatric FH Symposium in Lyon, France**. If you are a clinician in the lipids area, join us and your peers - paediatricians, lipidologists, endocrinologists and paediatric cardiologists - on May 25, 2024! Hosted at the Lyon Marriott Hotel Cité Internationale, this symposium offers an invaluable platform for delving into the latest advancements in atherosclerosis, familial lipid disorders including FCS, HoFH and elevated LP(a) and related vascular diseases. Gain insights into how these developments shape clinical guidelines while networking with experts in the field.

Remember, registration is free but closes on May 20, 2024. Don't miss your chance to be part of this enriching event!

Read more about it [here](#).

World Heart Federation (WHF)

WHF Advocates for Tobacco-Free World at COP10

At the Tenth Session of the Conference of the Parties to the WHO Framework Convention on Tobacco Control (FCTC), WHF emphasized full implementation of the Convention to safeguard public health. The conference adopted the Panama Declaration, reaffirming the conflict between public health and tobacco industry interests. COP10 addressed the environmental impact of tobacco, adopting a historical decision on Article 18 to protect the environment and public health. WHF looks forward to supporting efforts to end the tobacco pandemic.

Read more about it [here](#).

WHF's Emerging Leaders Programme 2024: Applications Now Open

Healthcare practitioners, researchers, and global health advocates are encouraged to apply for the World Heart Federation's (WHF) Emerging Leaders Programme 2024.

Focused on fixed-dose combination therapies for cardiovascular disease, this year's program offers participants a five-day seminar from October 28 to November 1, 2024, in Mombasa, Kenya. Join a vibrant community of over 200 leaders in cardiovascular health.

Seize the opportunity to make a difference in global health. Apply now and take part in shaping the future of cardiovascular care.

Read more about it [here](#).

European Patients Forum (EPF)

Join European Patients Forum in Shaping the Future of Healthcare

The European Patients Forum (EPF) invites individuals to envision a healthcare system where patients actively participate in shaping policies, provide insights into their needs, and contribute to decision-making processes. This commitment transcends mere vision; it's a dedicated pledge.

EPF firmly believes that the Patient Organisations' Manifesto, the cornerstone of EPF's EU Elections Campaign 2024, lays the groundwork for a truly person-centred healthcare system.

Join EPF in shaping the future of healthcare by signing the petition. Read more about it and sign the petition [here](#).



Sex Differences in Diagnosis, Treatment, and Cardiovascular Outcomes in Homozygous Familial Hypercholesterolemia

A recent cohort study in JAMA Cardiology examined potential sex differences in diagnosis, treatment, and cardiovascular outcomes in individuals with homozygous familial hypercholesterolemia (HoFH). Analysing data from the HoFH International Clinical Collaborators (HICC) registry spanning 751 patients across 38 countries, the study found no significant disparities in age at diagnosis or untreated LDL cholesterol levels between the sexes, except for a higher smoking prevalence in men. While men had a higher incidence of myocardial infarction (MI), both sexes received similar lipid-lowering treatments, including statins and lipoprotein apheresis. Notably, women exhibited a lower cumulative incidence of MI and lower all-cause and cardiovascular mortality compared to men, underscoring the importance of early diagnosis and treatment in mitigating cardiovascular risk in HoFH patients.

Read more about it [here](#).

Breaking the Chains of Lipoprotein Lipase Deficiency: A Pediatric Perspective on the Efficacy and Safety of Volanesorsen

Familial Chylomicronemia Syndrome (FCS) is a rare disease that leads to very high triglycerides in the blood (called 'hypertriglyceridemia'), due to a deficiency of an important enzyme, named in Latin words 'Lipoprotein lipase (LPL) deficiency'. The disease occurs in 1 per million, although LPL deficiency is likely underdiagnosed and may be 10 times more common. Very high triglycerides often lead to inflammation of the pancreas, called 'pancreatitis'. Repeated inflammation of the pancreas can lead to life-threatening situations. Patients are on a lifelong severely fat-restricted diet, so more is needed to improve their quality of life and safety. There is an urgent need for effective drug-therapy, and in the severest form, therapy that can be used early in life. This month, Prof Albert Wiegman with his peers from the Netherlands have published results of a drug - an apoC3 inhibitor - in a 13-year old girl. Her pancreas was constantly attacked by inflammation before she started the treatment, and after starting, these attacks almost disappeared, because the apoC3 inhibitor lowered her triglycerides by more than 70%!

Read more about it [here](#).

Impact of Elevated Lipoprotein(a) on Coronary Artery Disease Phenotype and Severity

Lp(a) Awareness Day in March and this publication is very timely. A recent study investigated the impact of elevated Lipoprotein(a) levels on coronary artery disease (CAD) severity in a real-world population. Analysing data from the LipidCardio study, which included 975 patients undergoing angiography at a tertiary cardiology centre, the study found that patients with higher baseline Lp(a) levels exhibited a more severe CAD phenotype. Compared to those with normal Lp(a) levels (<65 nmol/L), patients with elevated Lp(a) levels (≥ 150 nmol/L) had a higher prevalence of prior CAD, coronary revascularization, and vessel lesions, as well as higher SYNTAX-I and Gensini scores. These findings underscore the importance of considering Lp(a) levels in the clinical management of patients with CAD, suggesting potential implications for risk assessment and treatment strategies.

Read more about it [here](#).

**SAVE
THE DATE**

- **29 February** - International Rare Disease Day
- **7 March** - Make it or Break it – Communication in rare diseases webinar
- **21 March** - Ask me anything about Lp(a) webinar
- **24 March** - Lp(a) Awareness Day

- **26 March** - PerMed FH – an Innovative Research Project for Precision Medicine in FH Explained webinar
 - **4 May (NEW!) - HoFH Awareness Day**
 - **24-26 May** - World Heart Summit 2024, Geneva, Switzerland
 - **26-29 May** - EAS Paediatric FH Symposium, Lyon, France
 - **8-10 November** – FHEF Annual Network Meeting 2024
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